

**Adolescent Transition** 

# Get pumped for the future

Your continued cardiology care for young people

# Introduction

Moving on from The Royal Children's Hospital (RCH) can be a scary thought for you and your parents/ carers however ensuring that you are successfully linked in with an adult hospital for ongoing monitoring and care of your heart condition is important. This brochure will give you a better understanding of what to expect in the adult healthcare setting and help you to prepare for the transfer. Transition is a carefully planned process between your cardiology team at the RCH and the cardiology team at the adult service.

## Life at an adult hospital (The Alfred, The Royal Melbourne, The Austin, St Vincent's)

There may be many differences between the cardiology services at the RCH and adult healthcare. Sometimes change can be challenging but these tips can help make your transition to a new hospital an easier experience. This is an exciting stage of your life as you become an adult and take charge of your own health.

Here are some of the general differences you may come across:

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Paediatric services	Adult services	Tips	
Questions may be more directed towards your parents and they may tell your healthcare team answers to these questions on your behalf.	Questions about your health will be directed to you. You will be expected to know about your condition and your current health status.  On your first visit your cardian and post.	Be confident and honest in your answers and don't be afraid to ask if unsure about anything. It may be helpful to prepare your questions before your appointment and record this somewhere, eg your phone.	
	cardiac conditions and past operations are refreshed with you.	You can always have someone with you or you can be seen on your own.	
You may be used to seeing one cardiologist for many years, as well as a similar treating team.	You are likely to see many different cardiologists because they may be on rotation at different times. Over time you will see some familiar faces.	Know how to advocate for yourself and make sure you maximise your appointments by being clear about what your needs are and how they can help you.	
Your parents may manage most of your medications, ordering and payment.	You may need to organise your own medications and know when you need new scripts (including ordering and payment).	Know what your medications are for and the ordering process.  Make sure you have your own Medicare card too.	

Paediatric services	Adult services	Tips
Appointment letters are usually sent to your parents. Follow up appointments are usually organised by your parents.	Appointment letters will be sent to you. You may need to make your own travel arrangements and will be responsible for booking and rescheduling clinic appointments.	Allow plenty of time to get to your appointment.  If you live over 100km away from Melbourne, you may be able to access transport assistance through the Victorian Patient Travel Assistance Service (VPTAS).
		Know how to book and reschedule appointments and keep your parents in the loop as much as possible.
Appointments are likely to be more frequent.	Appointments are likely to be less frequent, unless you are unwell.	Keep track of your appointments and if you need to see a member of your healthcare team before your scheduled appointment, call your new healthcare team
You know where to go around the RCH and will mainly have children and young people around you.	This adult hospital will be new to you and you're likely to have much older people around you, as well as in clinics.	Try visiting your new adult health service before your specialist appointment, preferably before you transfer.
You may be linked into services within the hospital, eg dental, physios, dieticians.	You may be referred to services outside the hospital and will need to organise and keep track of these appointments yourself.	Request services as close to home as possible and make sure you know how to get there.
Services may cost less here.	You may be charged extra for items such as equipment and medication.	Ask about any extra costs before you transfer and if needed, request financial support.



	The Royal Children's Hospital	The Royal Melbourne Hospital	Monash Medical Centre	The Alfred
Transport	Car park available at a cost. On street parking available  Tram route numbers 55 and 59  Taxi rank at front of the hospital	<ul> <li>Car park limited, at a cost</li> <li>On street parking available</li> <li>Tram routes numbers 19, 59 and 55</li> <li>Bus route numbers 402 and 505</li> <li>Taxi rank on Grattan Street</li> </ul>	<ul> <li>Car park available at a cost. On street parking available</li> <li>Buses route numbers 733, 703 and 631</li> <li>Taxi rank at front of the hospital</li> </ul>	Car park available. Concessions may apply for card holders  Tram stop outside the hospital  Taxi rank on Commercial Road
Referral	Required from GP/other specialist	Initial referral from paediatric cardiologist/GP	Initial referral from paediatric cardiologist/GP	Initial referral from paediatric cardiologist/GP
Tests: ECG, Echo, CXR, Bloods	Routine tests are usually all completed on same day. Bloods always done in the morning prior to clinic appointment	Metro patients  • Tests completed prior to clinic  • Same day discussed based on need  Country/ Interstate patients  • Most tests same day  • Some may be requested locally	Metro patients  • Tests done on a separate day (usually two weeks prior to seeing specialist)  Country/ Interstate patients  • All tests done on the same day	All patients need to have bloods done at least a week prior to clinic appointment. This is so blood results are ready at clinic. All cardiology tests will usually be done on the same day or follow up a week later.

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Review by Consultant	Usually seen by the same specialist doctor and familiar treating team.	Often seen by different doctors. A/Professor Michael Cheung from the RCH attends most review clinics.	Sometimes seen by a different doctor, on rotation.	Will be seen by different doctors.
lent	More than one speciality clinic held at the one time.	More than one speciality clinic held at the one time.	One Cardiology Clinic held, but children and adults seen at the same location.	One outpatients' Cardiology Clinic (Heart Centre) however your specialist appointment with your cardiologist will be held somewhere else, depending on your heart condition.
Environment				Pre-transplant patients will be reviewed in the Heart Centre and post-transplant patients will be seen in the 3F Transplant Clinic.
				Pulmonary hypertension patients will be seen by the Respiratory Department.



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	Expectations	Discussion and questions directed to patient/parents/ family.	Discussion and questions directed to patient (you).  On your first visit your cardiac conditions and past operations are refreshed with you.  Each time you attend you need to have completed your test prior, usually at least an ECHO.	Discussion and questions directed to patient (you).	Discussion and questions directed to patient (you).
	Other				Two joint clinics with the RCH and The Alfred teams, plus one joint clinic 12-months post-transfer, at the Alfred's Young Adult Clinic.
Medication	/ongoing care	Parents manage therapy/plan of continuing care.	Patient needs to know name/ dosage and resupply of medications.  Patient is involved/ pro-active in all aspects of ongoing care.	Patient needs to know name/ dosage and resupply of medications.  Patient is involved/ pro-active in all aspects of ongoing care.	Patient need to know name/ dosage and resupply of medications.  Patient is involved/ pro-active in all aspects of ongoing care.

	The Royal Children's Hospital	The Royal Melbourne Hospital	Monash Medical Centre	The Alfred
Coordination /staff	Usually the same reception/nursing/medical staff present at review.	At clinic often different reception/ nursing/medical staff present at review.  Transitions nurse phone 9342 4553.	Sometimes different reception/ nursing/medical staff present at review.	Sometimes different reception/ nursing/medical staff present at review.
Inpatient expectation	Admission/ treatment/ care in familiar ward area by familiar staff.	Admission/ treatment/ care in different area/ward depending on type of admission with unfamiliar staff. Inpatient accommodation sharing with patients of other gender and ages.	Admission/ treatment/ care in different area/ward depending on type of admission with unfamiliar staff. Inpatient accommodation sharing with patient of other gender and ages.	Admission/ treatment/ care will mainly be in the Heart Failure Ward, but can depend on the type of admission. Unfamiliar staff when an in-patient, as well as ward sharing with patients of other gender and ages.

# Some common questions young people have:

- Q1. "How will they know about my complex medical history?" At first I was worried that the new cardiology team wouldn't know my history like my previous cardiologist who had seen me for years and years. My anxieties were reduced when I realised that the doctors had been in contact and read my referral letter which was very comprehensive. The doctor informed me that all my medical history was shared between the RCH and the adult hospital.
- Q2. "Do I have a say in where I'm transferred to?" A discussion will be held between your healthcare team and you about where your healthcare needs would be best catered for. It will also take into account where you are planning to live, work or study.
- Q3. "Will I get the same level of care?" The level of care never changes, however you will have more independence and responsibility for your own healthcare. If you are feeling unwell, it is up to you to notify your team, not your parents. All conversations about your healthcare will be directed to you either by mail or phone.
- Q4. "When will I be transferred?" There is no set day that a young person must transfer from the RCH, although the hospital's Access Policy states that transfer should occur between the ages of 18-19 or earlier depending on your personal circumstances. It is a decision that will occur between your healthcare team and yourself. As a cardiology patient, you will usually be transferred between the ages of 18 - 19, usually the point at which you finish secondary school and are settling into your new life adventure. This might involve working, studying, further education or travel.

It's normal for you to feel nervous about meeting your adult healthcare team for the first time however the cardiology team at the RCH will put together a referral (or transfer) letter and information for your new cardiology team in the adult service before you see them. Your new cardiology appointment is usually organised between six and twelve months of the referral. If you don't receive an appointment within six months, ask yourself "Have I changed my contact details?" and also contact the cardiology team at the adult healthcare service you're transitioning to. Ask your RCH team for the contact details of the adult healthcare service prior to or at your last appointment.

You can request a copy of the referral or transfer letter from your doctor before your final appointment at the RCH. This letter usually has a life span of three months from the date of your initial appointment and after that you will need to obtain a new referral from your GP which is valid for twelve or more months. Having a GP that you trust and can turn to for help is highly recommended.

Your doctor will send you to an adult healthcare setting where they believe you will receive the best care. Discuss with your RCH doctors what their transfer plans are for you so that you have an opportunity to have a say, as you may have some ideas which are different to your doctor's. Many of you may be seen by more than one doctor, so it's important to have these conversations with each of your doctors before you transfer.

Lastly before you leave the RCH remember to update all your contact details including Medicare details, your family or partner's details, your mobile number and local doctor (GP) details as these will be handed over to the new hospital. Your details will be required to register you into the new hospital's database and to enable them to contact you before your appointment.



The **timing** of your transfer could be dependent on:

- the current status of your health, ie if you're really unwell then transfer may be delayed or made sooner at the adult health service
- your age as transfer normally occurs when you are 18 or 19 years of age
- availability of the adult health service
- transfer information having been prepared and sent to the adult service
- your educational or vocational status, ie school, further education, work

#### Some helpful resources:

www.rch.org.au/transition

www.alfredhealth.org.au/Department.aspx?ID=131

www.rmh.mh.org.au/www/353/1001127/displayarticle/1001335.html

www.monashheart.org.au/page/About\_Us/

#### Support organisations:

www.heartkidsvictas.org.au

www.hearts4heart.net.au

### Who do I contact for more information?

If you have any questions about your personal transfer plan then contact your RCH cardiology team. If you have any concerns about what is involved with transfer then make sure you check out the Adolescent Transition website at www.rch.org.au/transition

#### Cardiology

The Royal Children's Hospital Melbourne 50 Flemington Road, Parkville Victoria 3052 Australia Telephone + 61 3 9345 5718 www.rch.org.au/cardiology

#### **Adolescent Transition Program**

The Royal Children's Hospital Melbourne 50 Flemington Road Parkville Victoria 3052 Australia Telephone + 61393454980 www.rch.org.au/transition

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